

Caregivers of ICU survivors at high risk of developing depression, emotional distress

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In a new Canadian study published on May 12 in the *New England Journal of Medicine*, lead author Dr. Jill Cameron, Affiliate Scientist at Toronto Rehabilitation Institute-University Health Network (UHN), highlights the need to consider the mental health of caregivers in post-ICU care. Credit: UHN

A new Canadian study focusing on caregiver outcomes of critically ill



patients reveals that caregivers of intensive care unit (ICU) survivors, who have received mechanical ventilation for a minimum of seven days, are at a high risk of developing clinical depression persisting up to one year after discharge.

The study, led by Dr. Jill Cameron, Affiliate Scientist at Toronto Rehabilitation Institute-University Health Network (UHN) highlights the need to consider the mental health of <u>caregivers</u> in post-ICU care. While caregiver assistance can be beneficial to <u>patients</u>, such care may have negative consequences for caregivers, including poor health-related quality of life, emotional distress, caregiver burden, and symptoms of <u>post-traumatic stress disorder</u>.

Published in the *New England Journal of Medicine* on May 12, 2016, the study's findings suggest patients' illness severity, functional abilities, cognitive status and neuropsychological wellbeing are not associated with caregiver outcomes. Alternatively, characteristics of the caregiver and individual caregiving situation play a significant role in determining outcomes over the follow-up year.

This study is part of Phase one of the RECOVER Program, a multiphase project, involving 10 intensive care units across Canada, co-led by Drs. Margaret Herridge, Scientist at the Toronto General Research Institute, and Cameron, in collaboration with the Canadian Critical Care Trials Group. The project aims to identify risk factors for patients and families with the goal of designing rehabilitation models to improve outcomes.

"In the world of critical illness, a lot of research has focused on making sure people survive - and now that people are surviving, we need to ask ourselves, what does quality of life and wellbeing look like afterwards for both patients and caregivers," says Dr. Cameron, also Associate Professor, Department of Occupational Science & Occupational



Therapy and Rehabilitation Sciences Institute, Faculty of Medicine at University of Toronto.

"We need to intervene and support caregivers of all patients, not just the 'sickest' patients. Caregivers are not a uniform body of individuals - they have different needs unique to their caregiving situation."

From 2007-2014, caregivers of patients who received seven or more days of mechanical ventilation in an ICU across 10 Canadian university-affiliated hospitals were given self-administered questionnaires to assess caregiver and patient characteristics, caregiver depression symptoms, psychological wellbeing, health-related quality of life, sense of control over life, and impact of providing care on other activities. Assessments occurred seven days and three, six and 12-months after ICU discharge.

The study found that most caregivers reported high levels of depression symptoms, which commonly persisted up to one year and did not improve in some. Caregiver sense of control, impact on caregivers' everyday lives, and social support had the largest relationships with the outcomes. Caregivers' experienced better health outcomes when they were older, caring for a spouse, had higher income, better social support, sense of control, and caregiving had less of a negative impact on their everyday lives.

Poor caregiver outcomes may compromise patients' rehabilitation potential and sustainability of home care. Identifying risk factors for caregiver distress is an important first step to prevent more suffering and allow ICU survivors and caregivers to regain active and fulfilling lives.

A parallel companion study evaluating patients led by Dr. Herridge, also a Professor of Medicine at University of Toronto has been published in the *American Journal of Respiratory and Critical Care Medicine*. This project showed that patients who had been on a mechanical ventilator



for one-week could be divided into disability risk groups using age and length-of-stay in an <u>intensive care</u> unit and that these groups determine one-year recovery and illuminate the details of functional disability in daily life.

"These findings will help patients and families make vital decisions about embarking on and also continuing treatment in an <u>intensive care unit</u>," says Dr. Herridge.

"We need to educate patients, families and the public about what we can realistically offer in terms of functional outcome and quality of life for those patients with complex critical illness and who may come to the ICU in a debilitated state or may be older. We want people to understand and make informed choices about their care, given their circumstances."

The next phase of this research will focus on developing models of rehabilitation to optimize patient recovery and a program for caregivers to better prepare them for their caregiving role, including education and information on community-based resources, access to home care, and how they can draw on social and psychological support.

Provided by University Health Network

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